

General

Title

Epilepsy: percentage of all visits for patients with a diagnosis of epilepsy with seizure type and epilepsy etiology or syndrome documented OR testing ordered to determine etiology of epilepsy, seizure type, or epilepsy syndrome.

Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of all visits for patients with a diagnosis of epilepsy with seizure type and epilepsy etiology or syndrome documented OR testing ordered to determine etiology of epilepsy, seizure type, or epilepsy syndrome.

Rationale

Knowing why a patient has epilepsy can have a profound impact on medical or surgical management, prognosis, and outcomes. To get to a proper etiologic or syndrome diagnosis, the physician must combine clinical features of the case with electroencephalographic findings, neuroimaging results, specific laboratory studies such as genetic testing, cerebrospinal fluid analysis, tissue biopsy and a search for other systemic disorders (Berg et al., 2010). Frequent data collection on seizure type, etiology, and syndrome classification is necessary for early identification and proper treatment for those with epilepsy

(England et al., 2012). Providing etiology to patients would address known economic disparities, and may decrease healthcare resource use as individuals who would otherwise present in emergency settings would have increased understanding of their epilepsy diagnosis (Meyer et al., 2012). Early detection of etiology would confirm treatment options and subsequently improve seizure freedom rates (Cusmai et al., 2011; Verbeek et al., 2011).

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines and represent the evidence base for the measure:

Epileptic seizures and epilepsy syndromes in children, young people and adults should be classified using a multi-axial diagnostic scheme. The axes that should be considered are: description of seizure (ictal phenomenology); seizure type; syndrome and aetiology (National Institute for Health and Clinical Excellence [NICE], 2012).

The seizure type(s) and epilepsy syndrome, aetiology, and comorbidity should be determined, because failure to classify the epilepsy syndrome correctly can lead to inappropriate treatment and persistence of seizures (NICE, 2012).

When possible, choose which antiepileptic drug (AED) to offer on the basis of the presenting epilepsy syndrome. If the epilepsy syndrome is not clear at presentation, base the decision on the presenting seizure type(s). Recommendation was based on Guideline Development Group (GDG) consensus (NICE, 2012).

The AED treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the child, young person or adult's lifestyle, and the preferences of the person and their family and/or carers as appropriate (see Appendix E in the original guideline document) (NICE, 2012).

If a patient is thought to have a diagnosis of epilepsy then the diagnosis should include a best estimation of seizure types (Pugh et al., 2007).

Opportunity for Improvement

There is a gap in known seizure etiology (Wicks & Fountain, 2012; Wasade et al., 2012; Fitzsimons et al., 2013). It is important for the epilepsy care provider to always document and address gaps in etiology or syndrome classification as treatment can be tailored appropriately thus decreasing potential complications from seizures (Cusmai et al., 2011; Verbeek et al., 2011; Hesdorffer & Begley, 2013). For example, after implementation of an epilepsy quality measure checklist in an epilepsy clinic without any other intervention, documentation of etiology increased from 66.3% to 87.5%, illustrating that the measure has the intended consequence of increasing compliance just by tracking it (Cisneros-Franco et al., 2013).

Evidence for Rationale

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Berg AT, Berkovic SF, Brodie MJ, Buchhalter J, Cross JH, van Emde Boas W, Engel J, French J, Glauser TA, Mathern GW, Moshé SL, Nordli D, Plouin P, Scheffer IE. Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE Commission on Classification and Terminology, 2005-2009. *Epilepsia*. 2010 Apr;51(4):676-85. [PubMed](#)

Cisneros-Franco JM, Díaz-Torres MA, Rodríguez-Castañeda JB, Martínez-Silva A, Gutierrez-Herrera MA, San-Juan D. Impact of the implementation of the AAN epilepsy quality measures on the medical records in a university hospital. *BMC Neurol*. 2013;13:112. [PubMed](#)

Cusmai R, Moavero R, Bombardieri R, Vigeveno F, Curatolo P. Long-term neurological outcome in children with early-onset epilepsy associated with tuberous sclerosis. *Epilepsy Behav*. 2011 Dec;22(4):735-9. [PubMed](#)

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Fitzsimons M, Dunleavy B, O'Byrne P, Dunne M, Grimson J, Kalra D, Normand C, Delanty N. Assessing the quality of epilepsy care with an electronic patient record. *Seizure*. 2013 Oct;22(8):604-10. [PubMed](#)

Hesdorffer DC, Begley CE. Surveillance of epilepsy and prevention of epilepsy and its sequelae: lessons from the Institute of Medicine report. *Curr Opin Neurol*. 2013 Apr;26(2):168-73. [PubMed](#)

Meyer AC, Dua T, Boscardin WJ, Escarce JJ, Saxena S, Birbeck GL. Critical determinants of the epilepsy treatment gap: a cross-national analysis in resource-limited settings. *Epilepsia*. 2012 Dec;53(12):2178-85. [PubMed](#)

National Institute for Health and Clinical Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. London (UK): National Institute for Health and Clinical Excellence (NICE); 2012 Jan. 117 p. (Clinical guideline; no. 137).

Pugh MJ, Berlowitz DR, Montouris G, Bokhour B, Cramer JA, Bohm V, Bollinger M, Helmers S, Ettinger A, Meador KJ, Fountain N, Boggs J, Tatum WO 4th, Knoefel J, Harden C, Mattson RH, Kazis L. What constitutes high quality of care for adults with epilepsy. *Neurology*. 2007 Nov 20;69(21):2020-7. [40 references] [PubMed](#)

Verbeek NE, van Kempen M, Gunning WB, Renier WO, Westland B, Lindhout D, Brilstra EH. Adults with a history of possible Dravet syndrome: an illustration of the importance of analysis of the SCN1A gene. *Epilepsia*. 2011 Apr;52(4):e23-5. [PubMed](#)

Wasade VS, Spanaki M, Iyengar R, Barkley GL, Schultz L. AAN Epilepsy Quality Measures in clinical practice: a survey of neurologists. *Epilepsy Behav*. 2012 Aug;24(4):468-73. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

Primary Health Components

Epilepsy; seizure type; epilepsy etiology; epilepsy syndrome

Denominator Description

All visits for patients with a diagnosis of epilepsy (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Patient visits with seizure type and epilepsy etiology or syndrome documented OR where testing was ordered to determine epilepsy etiology, seizure type, or epilepsy syndrome (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Importance of Topic

Epilepsy data is lacking. In 2012, the Institute of Medicine released *Epilepsy across the Spectrum: Promoting Health and Understanding*, detailing epilepsy research disparities and highlighting specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions and outcomes of epilepsy (England et al., 2012). The following statistics only touch on the magnitude of epilepsy given lack of research and stigma:

It is estimated 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually (England et al., 2012).

Epilepsy prevalence might be underestimated because of underreporting associated with repercussions and stigma in disclosing epilepsy (Kobau et al., 2012).

Common comorbidities among people with epilepsy include somatic (i.e., fractures, asthma, diabetes, and heart disease), neurological (i.e., stroke, Alzheimer's disease, autism spectrum disorders, chronic pain), and mental health conditions (i.e., mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality) (England et al., 2012; Kobau et al., 2008).

It is estimated the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) range from 1 of every 10,000 who are newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery (England et al., 2012).

People with epilepsy are more likely to be unemployed or unable to work, have low annual household incomes, be obese and physically inactive, and to smoke (England et al., 2012; Kobau et al., 2008).

People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications (Fountain et al., 2011; England et al., 2012; Kobau et al., 2008).

It is estimated the annual direct medical cost of epilepsy in the United States is \$9.6 billion. This estimate does not include community service costs or indirect costs from losses in quality of life and productivity (England et al., 2012).

Opportunities for Improvement

Additional data on opportunities for improvement and gaps in care specific to the epilepsy measures can be located in the updated epilepsy measures.

A review of 261 patient responses using the PatientsLikeMe survey system indicated a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy (Wicks & Fountain, 2012).

The Institute of Medicine noted several gaps in care and opportunities for improvement, including 1) timely referrals and access to treatments, 2) epilepsy care and prevention, 3) education of persons with epilepsy and their families, and 4) the stigma of epilepsy (England et al., 2012).

Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage (Englot et al., 2012).

Evidence for Additional Information Supporting Need for the Measure

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990-2008. *Neurology*. 2012 Apr 17;78(16):1200-6. [PubMed](#)

Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. *Neurology*. 2011 Jan 4;76(1):94-9. [PubMed](#)

Kobau R, Luo YH, Zack MM, et al. Epilepsy in adults and access to care--United States, 2010. *MMWR Morb Mortal Wkly Rep*. 2012 Nov 16;61(45):909-13. [PubMed](#)

Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. *Morb Mortal Wkly Rep Surveill Summ*. 2008 Aug 8;57(6):1-20. [PubMed](#)

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. *Neurol Clin Pract*. 2012 Dec;2(4):335-42. [PubMed](#)

Extent of Measure Testing

The new epilepsy measures are being made available without any prior testing. The American Academy of Neurology encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so.

Evidence for Extent of Measure Testing

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

Statement of Acceptable Minimum Sample Size

Does not apply to this measure

Target Population Age

Unspecified

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

All visits for patients with a diagnosis of epilepsy

Note: Refer to the original measure documentation for International Classification of Diseases, Ninth Revision (ICD-9), International Classification of Diseases, Tenth Revision (ICD-10), and Current Procedural Terminology (CPT) Evaluation and Management (E/M) service codes.

Exclusions

Unspecified

Exceptions

Patient has completed all appropriate testing and the etiology of epilepsy or epilepsy has been documented as unknown.

Patient has a contraindication to undergoing any testing.

Patient undergoing testing with results pending at time of visit.

Patient or caregiver declines to answer questions or undergo any testing.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Patient visits with seizure type and epilepsy etiology or syndrome documented OR where testing* was

ordered to determine epilepsy etiology, seizure type, or epilepsy syndrome

**Testing:* May include, but is not limited to electroencephalogram (EEG), video EEG, magnetic resonance imaging (MRI), laboratory testing or genetic testing.

Exclusions

Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Administrative clinical data

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Measure #2: etiology, seizure type, or epilepsy syndrome.

Measure Collection Name

Epilepsy Quality Measurement Set

Submitter

American Academy of Neurology - Medical Specialty Society

Developer

American Academy of Neurology - Medical Specialty Society

Funding Source(s)

American Academy of Neurology

Composition of the Group that Developed the Measure

Epilepsy 2014 Update Work Group Members

Co-Chairs: Nathan Fountain, MD; Paul C. Van Ness, MD

American Academy of Neurology: Jerome Engel, Jr., MD, PhD, FAAN; David S. Gloss, MD; Christiane Heck, MD, MMM; Diego A. Morita, MD; Marianna V. Spanaki, MD, PhD, MBA; Thaddeus Walczak, MD

American Academy of Family Physicians: Mark C. Potter, MD

American Academy of Pediatrics: Edwin Trevathan, MD, MPH

American Association of Neurological Surgeons/Congress of Neurosurgeons: Joseph Neimat, MD

American Association of Neuroscience Nurses: Mona Stecker, DNP, NP-BC, CNRN, SCRNP

American Board of Internal Medicine: Sharon M. Hibay, RN, DNP

American Clinical Neurophysiology Society: Susan T. Herman, MD

American College of Emergency Physicians: J. Stephen Huff, MD

American Epilepsy Society: Gabriel U. Martz, MD

American Society of Neuroradiology/American College of Radiology: Marvin Nelson, MD

Child Neurology Society: Inna Hughes, MD, PhD

Citizens United for Research in Epilepsy: Tracy Dixon-Salazar, PhD

Epilepsy Foundation: Janice M. Buelow, RN, PhD

National Academy of Neuropsychology: Daniel Drane, PhD, ABPP(CN)

National Association of Epilepsy Centers: Ramon Bautista, MD, MBA

OptumInsight: Kay Schwebke, MD, MPH, MA

Veterans Affairs Epilepsy Centers of Excellence: Karen Parko, MD, FAAN

Independent Representatives: Laurie A. Olmon; Mary Jo Pugh, PhD, RN

Work Group Facilitators: John R. Absher, MD, FAAN; Anup D. Patel, MD; Kevin N. Sheth, MD, FAHA, FCCM, FNCS

American Academy of Neurology Staff: Amy Bennett, JD; Gina Gjorvad; Becky Schierman, MPH; Rebecca J. Swain-Eng, MS, CAE

Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Endorser

American Epilepsy Society - Medical Specialty Society

Child Neurology Society - Medical Specialty Society

Epilepsy Foundation - Medical Specialty Society

Date of Endorsement

American Epilepsy Society: 2013 Jul 29

Child Neurology Society: 2014 Jul 29

Epilepsy Foundation: 2014 Aug 7

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jan

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

This measure updates previous versions:

American Academy of Neurology (AAN). Epilepsy physician performance measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2009 Aug 10. 50 p.
Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. Neurology. 2011 Jan 4;76(1):94-9.

Measure Availability

Source available from the [American Academy of Neurology \(AAN\) Web site](#) .

For more information, contact AAN at 201 Chicago Avenue, Minneapolis, MN 55415; Phone: 800-879-1960; Fax: 612-454-2746; Web site: www.aan.com .

NQMC Status

This NQMC summary was completed by ECRI Institute on December 16, 2011. The information was verified by the measure developer on January 30, 2012.

This NQMC summary was updated by ECRI Institute on January 6, 2016. The information was not verified by the measure developer.

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Production

Source(s)

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